Barriers to effective cancer pain management: a survey of Australian family caregivers

S. Aranda, Professor, P. Yates, PhD, RN, Associate Professor, H. Edwards, PhD, RN, Professor, R. Nash, MHLTHSC, RN, H. Skerman, MSOCSC, RN & A. McCarthy, MN, RN

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Cancer pain continues to be an important focus of health research and intervention development. The continuing shift of cancer care to the community increases the family caregiver's role in pain management and highlights the need to understand family experiences and also family barriers to effective pain management. This paper presents the findings of an Australian study exploring attitudinal barriers to effective pain management amongst 75 family caregivers of people with cancer attending an outpatient clinic. Approximately 75% of the caregivers demonstrated concerns or were unsure about addiction, a belief likely to impact on the use of prescribed opioids in the home. Caregivers demonstrated similar levels of concern about side-effects or whether the presence of pain indicated disease progression. These findings support research in other populations and are further evidence of the need to include family caregivers, along with patients, in intervention studies aimed at reducing the impact of these barriers on effective pain management.

Despite several decades of cancer pain research evidence continues to amass that pain in people with cancer remains a significant health problem (Yates et al. 2002). Attempts to understand the gap between our capacity to relieve cancer pain and the reality that many people with cancer continue to experience pain include approaches emphasizing improved medication prescribing (WHO 1996) and explorations of patient and health professional attitudinal barriers to effective pain management (Ward et al. 1993; Ward & Gatwood 1994; Ward & Hernandez 1994; O'Brien et al. 1996). Increasingly there is recognition that the family's and specifically the family caregiver's attitudes to cancer, cancer pain and pain management are important influences on the patient's cancer experience (Given et al. 2001). Critically the shift of cancer care to the community and outpatient settings increases the need for health professionals to fully understand the role of family caregivers in pain management (Cleeland et al. 1994). The aim of this paper is to present the findings of an Australian study exploring the barriers to effective pain management in family caregivers. The findings presented represent part of a larger effort to develop effective interventions to overcome attitudinal barriers to effective cancer pain management and represent the first Australian data on family barriers. This work complements recent Australian research on patient barriers to effective pain management by our group (Yates et al. 2002) and others (Potter et al. 2003). This emphasis on family caregivers as a critical part of the pain management process acknowledges the importance of the social context in which pain occurs.

The impact of pain

There is an abundance of research and clinical data confirming the detrimental consequences of inadequate cancer pain control in physical, emotional and social terms (Cleeland et al. 1994; Lancee et al. 1994; Ferrell 1995; Ferrell & Dean 1995;

Orr 2001). In addition to direct physical suffering, unrelieved pain may exacerbate other physical symptoms, compound anxiety and depression, disrupt interpersonal relationships or precipitate spiritual crises (Woodruff 1993; Woodruff 1996). Furthermore, social norms concerning the inevitability and severity of cancer pain underpin current arguments supporting the legalization of euthanasia. Those in favour of euthanasia routinely argue that unrelieved pain is a justification for the voluntary ending of life (Kissane et al. 1998; Kuuppelomaki 2000; Orr 2001; Kelly et al. 2002).

Cancer pain may be imbued with threatening meanings that do not arise with the benign pain caused by other conditions, and which may influence attitudes towards pain management (Chen 1999; Levin 1999). Despite improvements in treatment, there is a body of sociological literature and health research that suggests that cancer pain continues to be a metaphor for impending death (Ferrell 1995; Aranda 1999); inevitable physical deterioration and decay (Chen 1999); spoiled and stigmatized identity (Frank 1995); or that it signifies chaos due to its inherently uncontrolled and unpredictable trajectory (Kleinman 1988; Frank 1995).

Attitudes towards the opioids used to treat cancer pain are also known to play a significant role in cancer patients' reluctance to acknowledge pain and to adhere to recommended pain relief strategies. In addition concerns about side-effects, with being a good patient and beliefs that using morphine too early will limit options at the end of life all play a role in reducing the potential effectiveness of pain management (Ward et al. 1993; Ward & Gatwood 1994).

The importance of the family

Increasingly there is acknowledgement that the family's experience of cancer is relevant to our understandings of pain management and pain outcomes (Given et al. 2001). Recent international research highlights the impact of unrelieved cancer pain on family members' well-being (Miaskowski et al. 1997a; Lin 2001) and this can in turn affect their beliefs and attitudes towards cancer pain. Pain causes considerable distress to spouses (Berry & Ward 1995) and is associated with caregiver depression (Miaskowski et al. 1997b).

In addition international research has identified that family caregivers exhibit similar attitudinal barriers to optimal cancer pain management, as do the patients they support. Caregivers demonstrate a fear of addiction to opioids, concerns about opioid side-effects, a fear of injections and concerns that increasing pain is associated with disease progression (Berry & Ward 1995). In addition caregivers, like patients, exhibit problems in communicating pain to doctors because of a desire to be a 'good' patient (Pargeon & Hailey 1999).

Importantly, the shift of care from hospital to home has increased the extent to which family members are involved in pain management (Given et al. 2001; Aranda & Hayman-White 2001) and in turn has the potential to increase the burden on families. In our recent study of family caregiver's involvement in cancer pain management, 70% of the sample (n = 75) reported their level of involvement as moderate to a lot (Yates et al. 2004). The activities these caregivers reported included management of medications for almost half of the sample, indicating the important potential for family attitudinal barriers to influence adherence to pain medication prescriptions.

There is also evidence that family caregivers see themselves as an important component of the patient's pain management (Redinbaugh et al. 2002). On the down side this can mean that caregiver' attitudes result in conflicts about medications and decisions to withhold information from the health team, all as attempts to protect the patient from over use of pain medications (Taylor et al. 1993). However, on the positive side family members who display little concern about addiction, who understand there is no ceiling effect to opioids and who believe effective pain management is possible report less pain in the patient than those without these positive attitudes (Pargeon & Hailey 1999). This suggests that interventions aimed at reducing caregiver barriers to effective pain management may impact positively on patient pain outcomes. Thus understanding caregiver barriers is an important step in developing intervention approaches that include the family caregiver.

Aim of the study

The aim of this study was to explore the cancer pain beliefs and attitudes of a cohort of family caregivers of cancer patients in the outpatient setting. The study is premised on the belief that family caregivers are an important mediator of effective pain management.

Method

Design

The study comprises a substudy of a larger program of work aimed at developing psycho-educational interventions to improve cancer pain management. The particular study comprised a descriptive, exploratory cross-sectional survey of a cohort of family caregivers recruited over a 1-month period from a large public hospital in Brisbane, Australia. The sample comprised 75 family caregivers of people with cancer attending the oncology outpatient clinics at this hospital. This paper reports on responses from the larger survey to selected items that assessed family caregivers beliefs and attitudes to pain and pain management. Full details of the larger study have been reported elsewhere (Yates et al. 2004).

Inclusion criteria

Eligible participants were the family caregivers of patients, who met the inclusion criteria and who attended the outpatients department of a major metropolitan hospital during a 1-month period. Patient eligibility criteria included:

1 18 years of age or over;

2 ability to read and converse in English;

3 had experienced pain associated with cancer in the past month; and

4 had at least one family caregiver attending the outpatients department with the patient.

The family caregiver cohort of the study was identified as any significant other nominated as such by the person with cancer. Family caregiver eligibility criteria included the ability to read and converse in English and a minimum age of 18 years. Patients accompanied by more than one caregiver were asked to nominate the individual they considered their primary caregiver.

Instrument

Family caregivers completed a self-report questionnaire in two parts. Part 1 elicited baseline demographic data such as the family caregiver's age, gender, marital status, occupation and educational background. Part 2 explored respondents' perceptions of the experience of their relatives' cancer pain; and the caregiver's beliefs about and attitudes to effective pain management. This paper focuses on responses to questionnaire items assessing beliefs and attitudes to pain and pain management, which may act as barriers to effective pain management.

Beliefs and attitudes were assessed with the Barriers Scale developed by Ward and Gatwood (1994), which has been tested in a number of studies in the USA, Australia, and Taiwan. Four of the seven subscales of the Barriers Scale were included in this study as relevant to the Australian context and this population. Fifteen items assessed concerns about addiction, side-effects, tolerance to pain relieving medication, and pain as an indicator of progression of the illness. Family members rated their agreement with each item on a 5-point scale. The mean for each subscale was calculated and multiplied by 10, giving a range of scores from 10 to 50. In our previous studies (Yates et al. 2002), these subscales have Cronbach alpha scores ranging from 0.56 to 0.86. In the present study, alpha scores ranged from 0.47 to 0.87.

Procedure

Participants were consecutively recruited from attendees at the oncology clinics over the 1-month period. A trained research interviewer utilized a brief screening tool to determine patient eligibility for the larger study. Written and verbal information concerning the study were provided to prospective eligible patients, prior to the researcher obtaining the patient's written consent to participate, and their permission for the nurse to approach their family caregiver. The family caregiver was provided with similar information and invited to participate in the study. After full written consent was obtained, the patient and their caregiver completed separate questionnaires in quiet areas in the outpatient's clinic. The researcher provided assistance as necessary.

Data analysis

spss ® version 11 was utilized to generate descriptive statistics and frequency distributions for responses to all items, and to calculate alpha reliability coefficients for all subscales. Bivariate analyses (chi-square and independent t-tests) were conducted to assess relationships between demographic and clinical data, including age, income, and pain intensity, and family caregivers' beliefs and attitudes regarding pain and pain management.

Results

Caregiver profile

Full details of the demographic profile and pain characteristics of the sample are reported elsewhere (Yates et al. 2004). In summary caregivers had a mean age of 55 years (SD = 13.5), were predominantly female spouses living with the patient and having contact with them on a daily basis. These demographic characteristics are presented in Table 1.

Table 1.
Demographic characteristics of family member (n=75)

Characteristic	Frequency	%
Age		
19–40 years	12	16.0
41–50 years	15	20.0
51–60 years	19	25.3
61–70 years	23	30.7
71–80 years	6	8.0
Gender		
Male	19	25.3
Female	56	74.7
Marital status		
Married/partnered	61	81.3
Single(never married)	7	9.3
Separated/divorced/widowed	7	9.3
Weekly income		
$120–$229	13	17.3
$300–$499	25	33.3
$500–$699	11	14.7
$700–$999	6	8.0
$1000–$1499	4	5.3
$1500–$ 1999	1	1.3
$2000 or more	1	1.3
Unsure/not stated	14	18.7
Employment status*		
Pension	27	36.0
Working full-time	13	17.3
Full-time carer	11	14.7
Retired voluntarily	8	10.7
Working part-time	6	8.0
Retired due to family member's illness	2	2.7
Other	6	8.1
Highest postschool qualification*		
None	27	36.0
Certificate/diploma	31	41.3
Bachelor degree or higher	8	10.7
Trade/apprenticeship	6	8.0
Other	1	1.3
Relationship with patient		
Spouse/partner	51	68.0
Relative	22	29.3
Friend/carer	2	2.7

*Two missing values.

Caregivers were asked to rate, on a scale of 0 (no pain) to 10 (pain as bad as they could imagine), the average pain their family member had experienced during the previous week. The mean pain score was 5.5 (SD = 2.5), with 64% of respondents rating their family member's average pain as 5 or above, indicating that caregivers believed that pain was a significant problem for these patients.

Beliefs and attitudes towards pain and pain management

Table 2 summarizes the alpha reliability coefficient and mean overall score of each of the four subscales in the questionnaire. Table 3 details the responses to individual items in the subscales concerning addiction, side-effects, disease progression and tolerance. Table 3 indicates that approximately three quarters of family caregivers are concerned or unsure about addiction, side-effects or whether the presence of pain indicated progression of the disease. Of particular note in these results is the high proportion of caregivers indicating they were unsure about their attitudes and beliefs to various questions. For 11 of the 15 questions more than 29% of caregivers were unsure of their response (range 29.3-45.4%).

Addiction

The negative social norms attached to pain relieving medications are evident in the responses to this survey. For example, Table 2 demonstrates the predominance of caregiver fears concerning the dangers of addiction and misconceptions concerning the ease with which addiction occurs. Moreover, within the subscale exploring addiction in Tables 3, 30-47% of caregivers report commonly held misperceptions concerning the risk of addiction entailed in using medication to relieve cancer pain, while a further 30-45% report feeling unsure or certain about the likelihood of addiction. Significantly, males were more concerned about addiction than females (M = 34.7, SD = 6.5 and M = 30.9, SD = 8.7, respectively, $P < 0.05$).

Disease progression

Table 2 indicates that the second most common concern of family caregivers in this cohort is their perception that the experience of pain signifies the progression of the disease.

Table 2.
Beliefs and attitudes to pain relieving medication

Concerns	n	No of items	Alpha Mean	(SD)
Addiction	75	3	0.77	31.9 (8.3)
Progression	74	3	0.87	31.8 (8.4)
Side-effects	74	6	0.47	31.4 (5.0)
Tolerance	75	3	0.76	25.8 (7.8)

Range 10–50; high score = greater concern.

The most common belief in the disease progression subscale is that pain is an indicator that the disease is becoming worse (Table 3). Further examination of the family caregivers' perception of the patients' pain experiences and instrument subscales indicated that there is a relationship between respondents' rating of their

relatives' pain and concerns that the pain was an indicator of disease progression (r = 0.3; P = 0.006). As the caregiver's rating of the patient's pain increased so did their level of agreement that pain indicated disease progression.

Table 3.

Beliefs and attitudes of family caregivers towards pain and pain management

	Agree	Unsure	Disagree
Addiction			
There is a real danger of becoming addicted to pain relieving medication.	46.7	29.3	24.0
Pain medicine is very addictive.	9.3	45.4	25.4
People get addicted to pain relieving medication easily.	37.3	37.3	24.0
Side-effects			
Confusion from pain relieving medication is really a bother.	34.7	36.0	29.3
Nausea from pain relieving medication is really distressing.	57.3	29.3	13.4
Drowsiness from pain relieving medication is really a bother.	41.3	24.0	34.7
Pain relieving medication often makes you do embarrassing things.	47.3	41.9	10.8
Constipation from pain relieving medication is really upsetting.	85.1	6.8	8.1
It is easier to put up with pain than with the side-effects that come from pain relieving medication.	13.3	30.7	56.0
Progression			
Having pain means that the disease is getting worse.	38.7	38.7	22.6
The experience of pain is a sign that the illness has gotten worse.	36.5	40.5	23.0
Pain is a sign that the illness is worse.	33.3	38.7	28.0
Tolerance			
It's a good idea to 'save' pain medication for later when you might really need it.	14.7	13.3	72.0
If you take pain-relieving medication when you have some pain then it might not work as well if the pain becomes worse.	32.0	38.7	29.3
Pain relieving medication should be 'saved' in case the pain gets worse.	17.3	12.0	70.7

Side-effects

Concerns about the side-effects of pain medication were the third most common overall concern of family caregivers in this study (Table 2), with 35-85% of caregivers indicating concerns about side-effects (Table 3). However, on the positive side, caregivers did not believe that it was easier to put up with pain than with side-effects. The side-effects demonstrating the highest level of caregiver agreement were concerns about constipation (85%); nausea (57%); doing embarrassing things because of the medications (47%); and drowsiness (41%). Significantly greater concerns about side-effects are expressed by family members with no partner than those with partners (M = 34.1, SD = 3.8 and M = 30.8, SD = 5.0, respectively, P < 0.05). Additionally, caregivers under 55 years of age are more concerned about side-effects than those 55 years or more although this was not statistically significant (M = 32.5, SD = 5.3 and M = 30.4, SD = 4.5, respectively, P = 0.07).

Tolerance

Family caregivers in this study are least concerned with issues of tolerance and a misperception concerning the ceiling of opioid effectiveness (Table 2). Two of the three items in this subscale in fact reveal that more than 70% of respondents were not concerned about opioid ceiling (Table 3). The remaining item in this subscale, which is concerned with the titration of the dose according to the level of pain, contradicts the other items. Family caregivers with weekly incomes under $500 (M = 28.0, SD =

8.1) were more likely than those with higher incomes (M = 22.5, SD = 5.0) to believe that cancer patients develop a tolerance to pain relieving medication ($P < 0.01$).

Discussion

Many studies have explored cancer patients' beliefs and attitudes regarding pain. Relatively little research has examined the beliefs and attitudes of their family caregivers, particularly in Australia. However, there is some indication that caregiver perceptions will influence the way that they assist their relative to manage their pain and the ultimate efficacy of pain management interventions (Lin 2001).

Family members in this study were concerned or unsure about the addictiveness of pain relieving medications and perceived their relative's experience of pain to be a sign of progressive disease. Side-effects were also of concern, particularly constipation. Other concerns related to their relative's experience of nausea, saying and doing embarrassing things, drowsiness and confusion. These attitudes of family members to pain and pain relieving medications are in general consistent with those reported in the literature for the person with cancer pain and may reflect strongly held social attitudes towards pain.

Addiction

Caregiver misperceptions regarding addiction in this study are consistent with those of family caregivers overseas (Berry & Ward 1995; Elliott et al. 1996; Ward et al. 1996; Lin 2001). Such attitudes may result in under medication of patients by caregivers and this study suggests this concern may be increased if the caregiver is male. While it is debatable whether family caregivers' beliefs regarding the dangers of addiction influence the opioid usage of relatively independent cancer patients (Ersek et al. 1999), it is more likely that caregiver misconceptions will have an effect on patients who need others to encourage their medication use or are reliant on caregivers to administer it. Lin (2001), for example, reported that caregiver hesitation to administer analgesia was positively correlated with the belief that pain medication is addictive.

Caregivers are less likely to be concerned with the possibility of addiction, however, if they understand the principles underlying opioid tolerance and the need for upward titration of the dose commensurate with pain severity (Elliott et al. 1996). It is apparent therefore that in addition to allaying fears about addiction attention needs to be placed on clarifying the differences between addiction and tolerance.

Progression

Similar to the findings of this study, overseas research indicates that a belief that worsening pain is a sign of disease progression will influence the caregivers' perception of the pain experience. It therefore rates highly as a barrier to effective pain relief when caregivers are reluctant to admit that the cancer is progressing and that more medication is required (Berry & Ward 1995; Ward et al. 1996; Lin 2000; Lin et al. 2000). It therefore may be important to elicit whether caregivers have fears of disease progression when assessing their contribution to pain management. It is known, for example, that in order to avoid the reality of disease progression, family

caregivers may deny that the patient is in pain and subsequently compromise pain relief (Ferrell et al. 1993).

Side-effects

The problems caused by the side-effects of pain medication generally rank between the first and third most important concerns of the family caregivers of both ambulatory and hospice cancer patients in other studies (Berry & Ward 1995; Ward et al. 1996; Lin et al. 2000; Lin 2001). In terms of the ranking of side-effects, caregivers in other studies tended to rate the specific side-effects of constipation and impaired cognitive function as problematic as the caregivers did in this study (Berry & Ward 1995; Ward et al. 1996; Lin 2000; Lin et al. 2000). We support previous recommendations that pain management education strategies should include an explanation of how these common side-effects of analgesics decrease over time, and the relative ease with which they are pre-empted (Thomason et al. 1998).

Tolerance

Family caregivers' concerns about analgesic tolerance are considered significant barriers to effective cancer pain management in similar studies (Berry & Ward 1995; Elliott et al. 1996; Lin 2000). Moreover, the relationship between lower income and concerns about drug tolerance reported here is supported by other data (Ward & Hernandez 1994).

Caregivers in this study rated their perceptions about tolerance their least concern overall although the responses showed some inconsistency. While only 29% of caregivers disagreed that taking pain relieving medication for some pain may mean it does not work as well when the pain gets worse, in contrast 71% disagreed that pain medication should be saved for when the pain gets worse and 72% disagreed that it was a good idea to save medication for when you really need it. Explanations for this inconsistency are not readily apparent but certainly the relative unconcern about tolerance in this cohort may offer a useful starting point for intervention work. For example, misconceptions about tolerance may link to problems of titrating medication dosage upwards for more severe pain that may be addressed in intervention work (Yeager et al. 1995). While this Australian cohort had positive belief and attitude scores compared to their overseas counterparts concerning drug tolerance, their misperceptions regarding the dose ceiling of pain medication is as problematic as similar perceptions reported elsewhere (Berry & Ward 1995; Elliott et al. 1996; Lin 2000). This is an important consideration in pain management education strategies, as it has been reported that family caregivers who do understand the need for upward dose titration and the lack of an opioid dose ceiling are more likely to have family members with better pain control (Elliott et al. 1996).

Conclusion and recommendations

This study presents findings from a relatively small consecutively recruited sample of caregivers who were attending an outpatient cancer clinic with their relative. Many of the measures have also not previously been used with this population, and some barriers scales demonstrated limited internal consistency. The extent to which the findings are generalizable is therefore difficult to ascertain. However, despite these

limitations, the findings of this study support previous work on barriers to effective pain management. The presence of significant concerns about addiction, the relationship between pain and disease progression and the problem of opioid side-effects in this group of family caregivers reinforces the need to address these issues as part of the total approach to patient pain management. The increasing role of the family in managing the patient's pain in the home environment and a recognition that family beliefs and attitudes will influence the success of their role adds to the growing call for intervention development that includes the family caregiver as a target of such work.

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References

Aranda S. (1999) A pain assessment approach to nursing the person with complex pain. In: Palliative Care Nursing: A Guide to Practice (eds Aranda S. & O'Connor M.), pp. 177-195. Ausmed, Melbourne.

Aranda S. & Hayman-White K. (2001) Home caregivers of the person with advanced cancer: an Australian perspective. Cancer Nursing 24, 300-307.

Berry P.E. & Ward S.E. (1995) Barriers to pain management in hospice: a study of family caregivers. Hospice Journal 10, 19-33.

Chen M. (1999) Validation of the structure of the perceived meanings of cancer pain inventory. Journal of Advanced Nursing 30, 344-351.

Cleeland C.S., Gonin R., Hatfield A.K., Edmonson J.H., Blum R.H., Stewart J.A. & Pandya K.J. (1994) Pain and its treatment in outpatients with metastatic cancer. New England Journal of Medicine 330, 592-596.

Elliott B.A., Elliott T.E., Murray D.M., Braun B.L. & Johnson K.M. (1996) Patients and family members: the role of knowledge and attitudes in cancer pain. Journal of Pain and Symptom Management 12, 209-220.

Ersek M., Kraybill B.M. & Pen A.D. (1999) Factors hindering patients' use of medications for cancer pain. Cancer Practice 7, 226-232.

Ferrell B.R. (1995) The impact of pain on quality of life. A decade of research. Nursing Clinics of North America 30, 609-624.

Ferrell B.R. & Dean G. (1995) The meaning of cancer pain. Seminars in Oncology Nursing 11, 17-22.

Ferrell B.R., Taylor E.J., Grant M., Fowler M. & Corbisiero R.M. (1993) Pain management at home: struggle, comfort, and mission. Cancer Nursing 16, 169-178.

Frank A.W. (1995) The Wounded Storyteller: Body, Illness and Ethics. University of Chicago Press, Chicago.

Given B.A., Given C.W. & Kozachik S. (2001) Family support in advanced cancer. CA: a Cancer Journal for Clinicians 51, 213-231.

Kelly B., Burnett P., Pelusi D., Badger S., Varghese F. & Robertson M. (2002) Terminally ill cancer patients' wish to hasten death. Palliative Medicine 16, 339-345.

Kissane D., Street A. & Nitschke P. (1998) Seven deaths in Darwin: case studies under the Rights of the Terminally Ill Act, Northern Territory, Australia. Lancet 352, 1097-1102.

Kleinman A. (1988) The Illness Narratives: Suffering, Healing and the Human Condition. Basic Books, New York.

Kuuppelomaki M. (2000) Attitudes of cancer patients, their family members and health professionals toward active euthanasia. European Journal of Cancer 9, 16-21.

Lancee W.J., Vachon M.L.S., Ghadirian P., Adair W., Conway B. & Dryer D. (1994) The impact of pain and impaired role performance on distress in persons with cancer. Canadian Journal of Psychiatry 39 (December), 617-622.

Levin R. (1999) Cancer and the self: how illness constellates meaning. In: Health Studies: a Critical and Cross-Cultural Reader (ed. Samson C.). Blackwell, Oxford.

Lin C. (2000) Barriers to the analgesic management of cancer pain: a comparison of attitudes of Taiwanese patients and their family caregivers. Pain 88, 7-14.

Lin C. (2001) Congruity of cancer pain perceptions between Taiwanese patients and family caregivers: relationship to patients' concerns about reporting pain and using analgesics. Journal of Pain and Symptom Management 21, 18-26.

Lin C., Wang P., Lai Y., Lin C., Tsai S. & Chen T.T. (2000) Identifying attitudinal barriers to family management of cancer pain in palliative care in Taiwan. Palliative Medicine 14, 463-470.

Miaskowski C., Kragness L. et al. (1997a) Differences in mood states, health status, and caregivers of oncology outpatients with and without cancer-related pain. Journal of Pain and Symptom Management 13, 138-147.

Miaskowski C., Zimmer E.F. et al. (1997b) Differences in patients' and family caregivers' perceptions of the pain experience influence patient and caregiver outcomes. Pain 72, 217-226.

O'Brien S., Dalton J.A. et al. (1996) The knowledge and attitudes of experienced oncology nurses regarding the management of cancer-related pain. Oncology Nursing Forum 23, 515-521.

Orr R.D. (2001) Pain management rather than assisted suicide: the ethical high ground. Pain Medicine 2, 131-137.

Pargeon K.L. & Hailey B.J. (1999) Barriers to effective cancer pain management: a review of the literature. Journal of Pain and Symptom Management 18, 358-368.

Potter V.T., Wiseman E., Dunn S.M. & Boyle F.M. (2003) Patient barriers to optimal cancer pain control. Psycho-Oncology 12, 153-160.

Redinbaugh E.M., Baum A., DeMoss C., Fello M. & Arnold R. (2002) Factors associated with the accuracy of family caregiver estimates of patient pain. Journal of Pain and Symptom Management 23, 31-38.

Taylor E.J., Ferrell B.R., Grant M. & Cheyney L. (1993) Managing cancer pain at home: the decisions and ethical conflicts of patients, family caregivers, and homecare nurses. Oncology Nursing Forum 20, 919-927.

Thomason T.E., McCune J.S., Bernard S.A., Winer E.P., Tremont S. & Lindley C.M. (1998) Cancer pain survey: patient-centered issues in control. Journal of Pain and Symptom Management 15, 275-284.

Ward S.E., Berry P.E. & Misiewicz H. (1996) Concerns about analgesics among patients and family caregivers in a hospice setting. Research in Nursing and Health 19, 205-211.

Ward S. & Gatwood J. (1994) Concerns about reporting pain and using analgesics: a comparison of persons with and without cancer pain. Cancer Nursing 17, 200-206.

Ward S.E., Goldberg N., Miller-McCauley V., Mueller C., Nolan A., Pawlik-Plank D., Robbins A., Stormoen D. & Weissman D.E. (1993) Patient-related barriers to management of cancer pain. Pain 52, 319-324.

Ward S.E. & Hernandez L. (1994) Patient-related barriers to management of cancer pain in Puerto Rico. Pain 58, 233-238.

WHO (1996) Cancer Pain Relief, 2nd edn, with a guide to opioid availability. WHO, Geneva.

Woodruff R. (1993) Palliative Medicine. Asperula, Melbourne.

Woodruff R. (1996) Cancer Pain. Asperula, Melbourne.

Yates P., Edwards H., Nash R., Walsh A., Fentiman B.J., Skerman H. & Najman J.M. (2002) Barriers to effective pain management: a survey of cancer patients in Australian hospitals. Journal of Pain and Symptom Management 23, 393-405.

Yates P., Aranda S., Edwards H., Nash R., Skerman H. & McCarthy A. (2004) Family caregivers' experiences and involvement with cancer pain management. Journal of Palliative Care (in press).

Yeager K.A., Miaskowski C., Dibble S.L. & Wallhagen M. (1995) Differences in pain knowledge and perception of the pain experience between outpatients with cancer and their family caregivers. Oncology Nursing Forum 22, 1235-1241.